

# The expanding role of the paediatric endocrinology specialist nurse

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# Disclosures

- Merck
- Ipsen
- Ferring

# Introduction

- History of nursing in the UK
- Nursing stereotype
- Advanced nursing roles
- Nursing in paediatric endocrinology

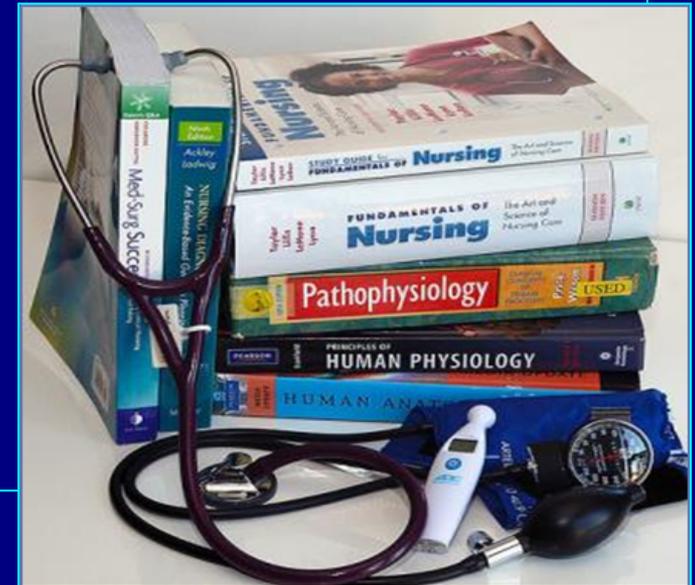


# History of nursing in the UK

- First school of nursing established in 1860
- 1940s
  - State Enrolled Nurse (SEN)
    - 2 years training
  - State Registered Nurse (SRN)
    - Registered General Nurse (RGN)
  - Launch of National Health Service (NHS)
- 1960s
  - First degree in Nursing

# History of nursing in the UK

- 1990s
  - Diploma 3 year training
  - Post graduate education introduced
- 2000s
  - All graduate profession
  - Training university based
  - MSc level education
    - Doctorate / Phd

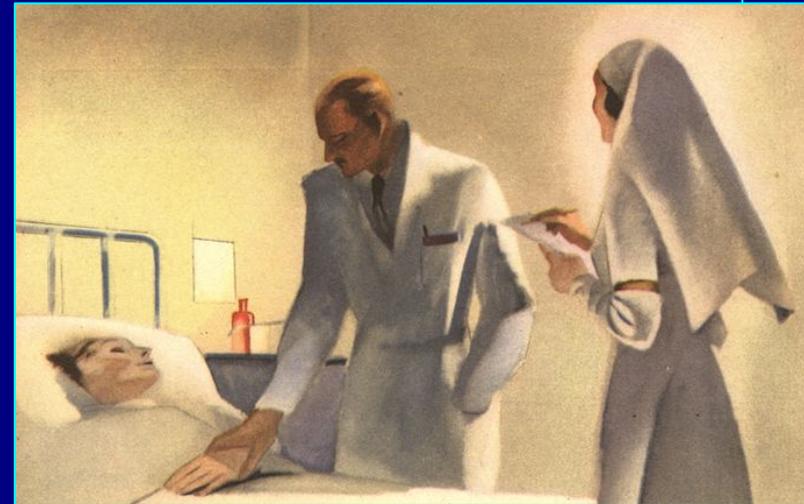


# Nursing stereotypes



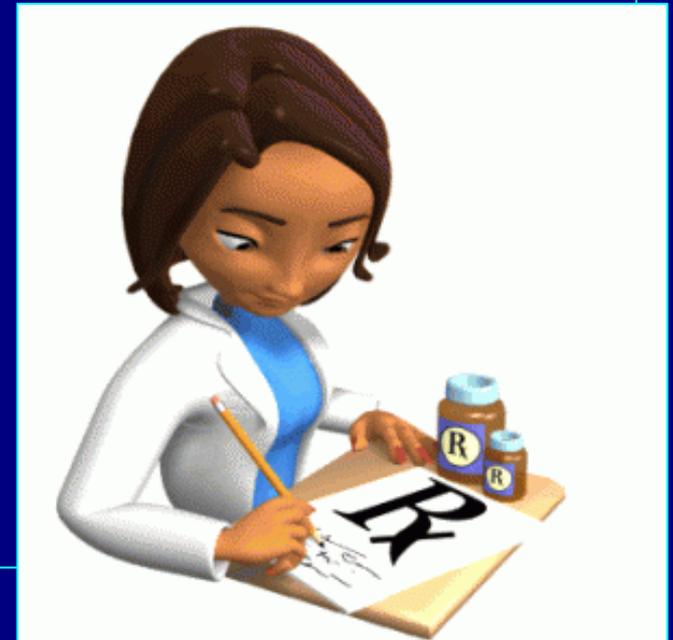
# Nursing Stereotypes

- Doctors Handmaidens
  - Do nurses actually work *for* doctors
    - Training and education
    - Recruitment
    - Management structure
  - Co-workers
  - Daily care of patients
    - Liaison between patients and doctors
  - Autonomous profession

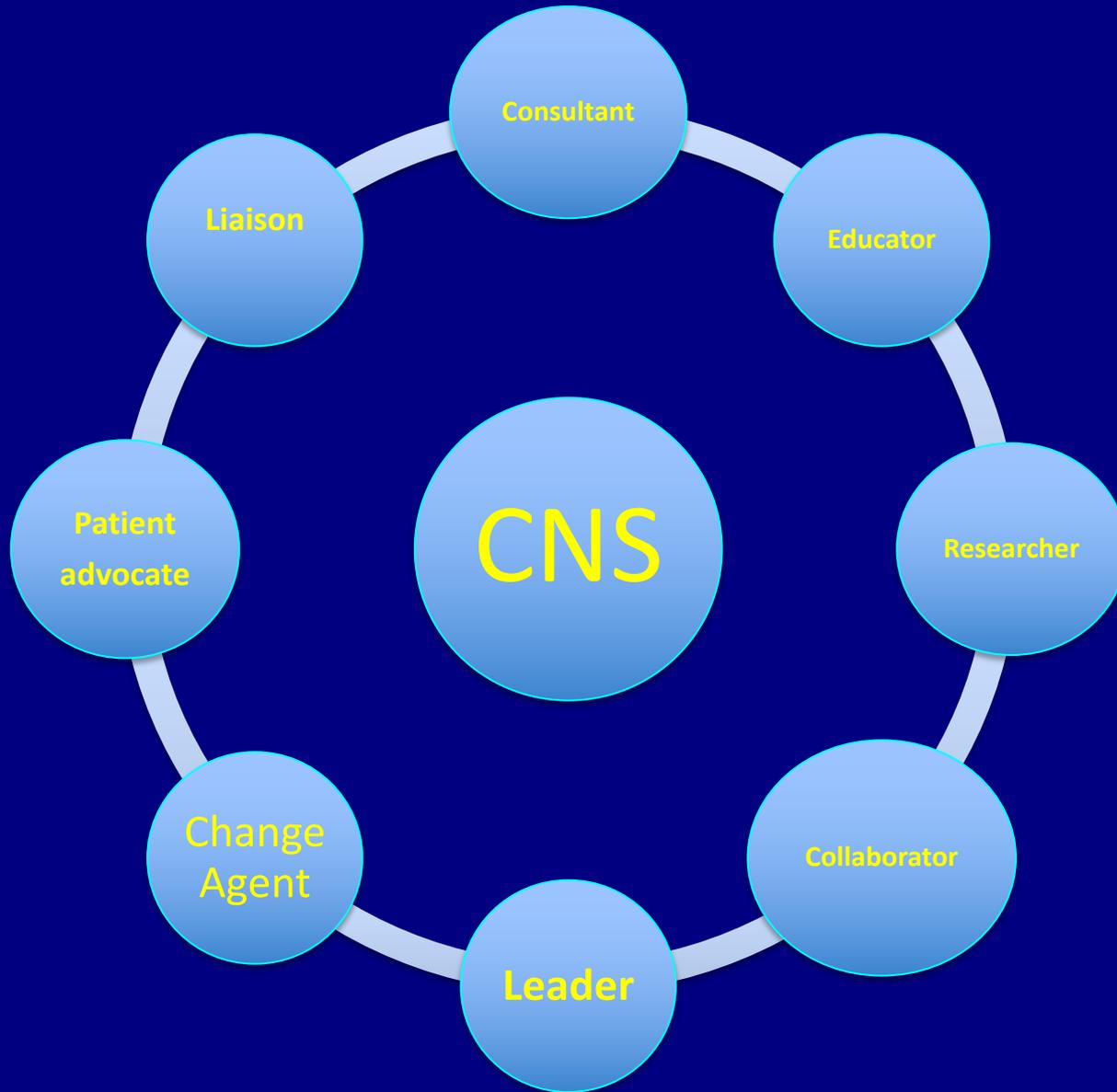


# Autonomy → Advanced practice

- Clinical Nurse Specialists
- Advanced Nurse Practitioners
  - Advancing roles
  - Expanding skills



# Clinical Nurse Specialist roles



# Guidelines for practice

*RCN Competencies*



Royal College of Nursing

Competencies:  
an integrated career and competency framework for paediatric endocrine nurse specialists



- Focus on knowledge, skills and interventions specific to endocrine nurses
- References local and national guidelines
- Adheres to Benner's (1982) 'Novice to Expert' concept
  - Competent practitioner
  - Experienced practitioner
  - Expert practitioner

# Education for advanced practice

- Post-graduate pathways
- BSc
- MSc
  - Children's Advanced Nurse Practitioner



# Children's Advanced Nurse Practitioner

- 3 year MSc course
- Accredited by the RCN
- Specialising in specific fields





# Furthering education in paediatric endocrinology

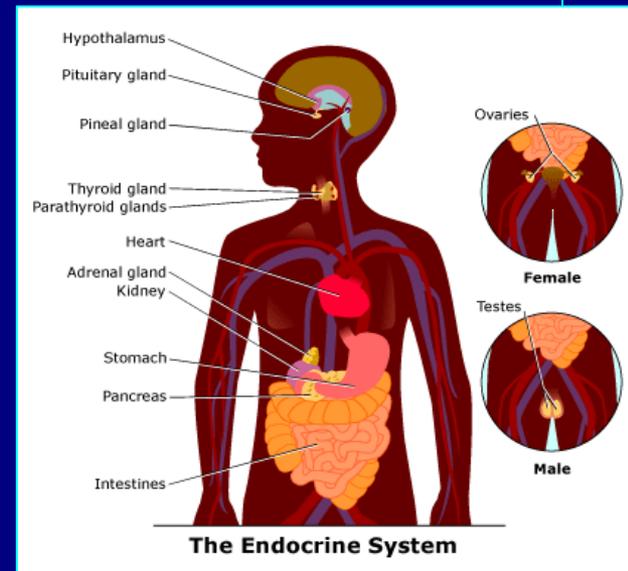
- Auxology course – St Bartholomew's and The Royal London Hospitals
  - Growth measurement
  - Bone age reading
  - Growth clinic
- BSc Module – Keele University
- BSc / MSc module – London South Bank University





# Module content

- The endocrine system
- The multidisciplinary team
- Growth and the IGF-1 system
- Puberty
- Adrenal disorders
- Disorders of Sex Development
- Thyroid disorders
- Disorders of salt and water balance
- Pancreas disorders
- Bone metabolism and bone health
- Late effects of childhood cancers
- Hormone replacement treatment
- Advanced nursing roles in paediatric endocrinology





# Nurse led care

- Outpatients
  - Nurse led clinics
    - Outpatients
    - Telephone
- Daycare
  - Nurse led investigations
  - GH choice and training
  - Emergency hydrocortisone training



# Benefits of nurse led clinics

- Decreases patients' waiting times
  - Including the nurse led clinic
  - GH prescribing process
- Increases consultants' time for more complex patients
- Building stronger relationships with patients and their families
- Enhanced patient satisfaction

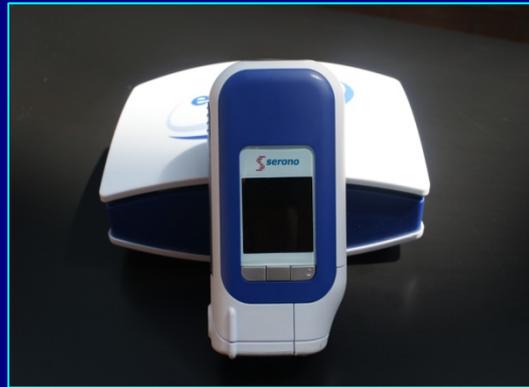


# Growth hormone and the CNS

Patient choice

Concordance

# GH devices



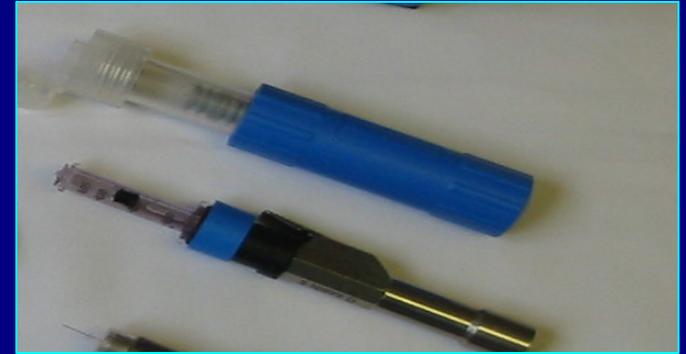
Introducing the NEW  
**HumatroPen™**

- Precision Dosing
- Flexibility to dose in small units
- Available in 3 colour coded pens

HumatroPen™ 6 mg  
HumatroPen™ 12 mg  
HumatroPen™ 24 mg



# Needle free devices



# Knowing our patients

- What is the CNS role in patient choice of growth hormone product?
  - Relationships with families
  - In depth knowledge about the condition
  - In depth knowledge regarding the product



# Patient choice – what are the issues?

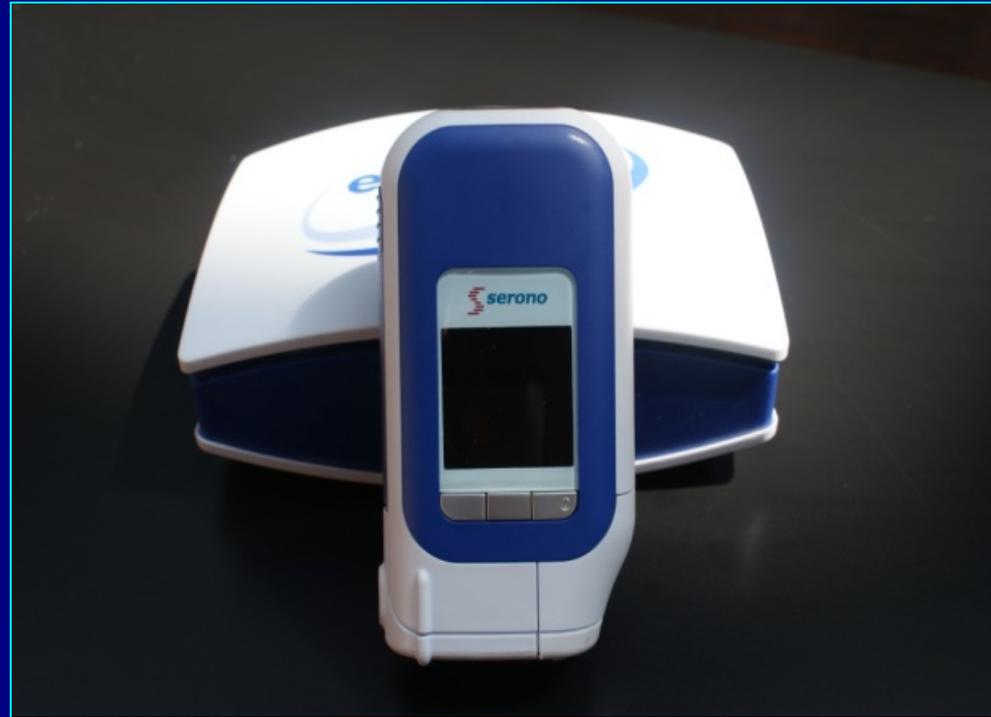
- Ease of use
- Needle free
- Colour
- Quietness
- Size
- Needle guard
- 'Feel'
- Automatic needle insertion
- Reduced time holding device against the skin post injection

*Wickramasuriya, 2005*

# Easypod

- 'Very useful' features:
  - Pre-programmed dose feature
  - Skin sensor
  - On screen instructions
  - Display of remaining dose
  - Confirmation of injected dose
  - Automatic needle attachment

*Dahlgren, 2007*



# Difference of opinion?

- Various comfort settings
- Dose history
- 'Teach Me' menu
- Multi-lingual instructions
  
- Refrigeration
- Homecare
- Reconstitution



# How well do we know our patients?

- Need to understand parental perceptions and beliefs concerning illness and treatment
- Discussions of the patients' view of the disease and their expectations of the treatment
  - Shown to increase concordance

*Spoudeas, 2014; Van Dongen, 2012; Cutfield, 2011; Haverkamp, 2008;  
Kapoor, 2008*

# Nurse / Doctor influence?

- Do we always know what is best for our patients?
- Need a thorough, more detailed understanding
- Nurses in the prime position to know the children and their families more closely
  - Families have our contact details
  - Contact us with queries / concerns
  - Main point of liaison for families



# But how does this work in practice?

- Children with learning difficulties
  - Septo Optic Dysplasia
    - Need for quick injection → Zomajet
    - Visual problems → Easypod, digital pen devices
- Teenagers
  - Something small, discreet, disposable → Miniquick
- Girls with Turner syndrome
  - Manual dexterity issues → Easypod, Zomajet
  - Larger doses needed → Easypod, Humatropen (20,24mg)
- Travelling families / children with more than one home
  - Think about non-refrigeration → Easypod, Miniquick, Norditropin

# But how does this work in practice?

- SGA
  - Reduced s/c fat →
    - Want more control over administering the injection
      - No autoinjectors
      - Smallest needle, small vial sizes (4mg, 5mg, 5.3mg)
- Control taken away → Easy pod
- Post oncology patients → Zomajet
- Fear of needles
  - Needle free → Zomajet
  - Needle covers / hidden needle → Easy pod, Nutropin Aq, Genotropin pen and Miniquick, Nordipenmate, SurePal

# How does choice work around the UK?

- Department has limited choice v.
- Free choice of all devices
  - Do we all give patient choice?
    - 89% of 52 centres surveyed do (BSPED audit 2008/2009)
- CNS
  - Chat in clinic
  - Demonstrates all devices
  - Posts out DVDs / patient literature – follow up phone call
  - Clinic appointment

*Informed choice?*

# Nurses' roles – how to increase concordance

- Initial meeting with children and families Non judgemental, flexible approach
- Spend time with the child and family
  - Get to know their concerns and fears
  - Get the concordance agreement right
- Free patient choice of device?
- Enhanced support
- Education for patients
- Nearing adolescence
  - *Opinions on their device may change..*

*Smith, 1992; Haverkamp, 2008; Kapoor, 2008; Cutfield, 2011*

# How can we enhance the choice process?

- ? Involve other patients
  - GH support days
  - Group demonstration sessions
- ? Courses for children for self-administration
  - Age 10 / 11
- Freedom of choice of all devices
- Explore technology
  - Text messaging
  - Apps

*Spoudeas, 2014; Van Dongen 2012;  
Kirk, 2010*



# Conclusion

- Paediatric Endocrine Nurse Specialists are in the best position to foster a close relationship with children and their families
- Advanced nursing roles
  - Nurse led clinics
  - Advance patient care with more time
    - Educate the children and families more on their condition, and about GH devices
    - Get to know the families and the implications of their conditions
    - More and more CNSs becoming Independent Prescribers and Advanced Nurse Practitioners

*Are we the future...?*